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A PILOT STUDY OF CANCER SURVEILLANCE IN CENTRAL ILLINOIS

Document No. 84/10

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Illinois Department of
Energy and Natural Resources

James R. Thompson, Governor
Michael B. Witte, Director

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A PILOT STUDY OF CANCER SURVEILLANCE IN CENTRAL ILLINOIS

by

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NOTE

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PREFACE

Cancer, a complex group of diseases, is the second leading cause of death in the United States and in Illinois. The chance that a person now under the age of twenty will develop cancer at some time in his life is about one in three. Approximately one half of those who develop cancer die from the disease or complications associated with it. Thus, if cancer were eliminated, the average length of life might increase by as much as two years. Approximately 1.8 million work-years would be gained, and over $18.9 billion dollars saved. The emotional costs cannot be estimated.

Cancer surveillance programs are being established in many states in order to determine the magnitude of the cancer experience at a level where policy and health programs can respond to restrain its occurence and modify its effects. Illinois has not developed a cancer surveillance program so there is no precise count of how many new cancer patients are diagnosed in the Illinois population each year. From the experience of other similar states and based on data obtained through the Surveillance, Epidemiology and End Results (SEER) program at the National Cancer Institute (NCI) we estimate that about 44,000 new cases will be diagnosed among the Illinois population in 1984.

To address the need to know more about the experience of cancer among the population of Illinois, the Illinois Department of Energy and Natural Resources, working together with the Illinois Department of Public Health contracted with the Illinois Cancer Council in 1980-81 to conduct a feasibility study to determine whether cancer reporting could be carried out in Illinois and which of several possible methods of case ascertainment would be most effective. The three methods examined were: obtaining the case information from hospital discharge data, conducting a periodic sample survey of hospitals to obtain data and then estimate the incidence, and establishing a case registration program and state registry of all newly-diagnosed cases. Based on the experience of others and our review of the feasibility of each approach, it was recommended that the case registration approach be subjected to further study. Beginning in November 1981, the Departments supported the Cancer Surveillance Pilot Study for East Central Illinois.

INTRODUCTION

This is the final report of a three year study, "Cancer Surveillance in East Central Illinois". The study was designed to test a model cancer surveillance system in a defined geographic area. There were three aims:

a) to determine whether a system based on voluntary reporting by hospitals is feasible;

b) to evaluate the relative costs and quality of several forms of case ascertainment;

c) to estimate the overall and per case costs of operating a statewide registry and to recommend procedures for implementing and carrying it out.

In developing this model, the Illinois Cancer Council has drawn on experience of almost ten years as coordinator of a regional cancer registration system linking four medical schools and as a participant in a national cancer data system linking the 21 comprehensive cancer centers established in the United States. In addition we obtained consultation and advice from staff of the SEER program at NCI, and from registry personnel in Florida, California, New Jersey, Colorado, Michigan, Pennsylvania, and Washington where state or regional registries have been established.

The model that was piloted in this project was "population-based" which means that it is based on complete reports of all diagnosed cancer cases in a specified population. Operationally, to obtain complete data for a defined population all health care facilities where a cancer might be diagnosed are regularly contacted and information on new diagnoses are obtained. In addition all facilities outside the region that might see residents of the region and diagnose a cancer are contacted and data obtained on such diagnoses.

Population-based data are required to provide information on the complete cancer experience of the region. They are used to:

a) Determine incidence and prevalence rates for the region. Incidence is defined as the number of newly-diagnosed cases in a given population during a particular year. Prevalence is the total number of cases, both newly-diagnosed and continuing, that exist in a population during a given year.

b) Specify these rates by race, age, sex, place of residence, and other selected demographic factors.

c) Monitor changes in these rates over time.

d) Monitor stage of disease at initial diagnosis thereby identifying areas where cancer prevention, detection, or public health education is needed for cancer control.

e) Evaluate the effects of programs aimed at promoting the control of cancer.

f) Establish baseline data and population parameters for initiation of etiologic and preventive studies that will reduce the risk of developing cancer among certain segments of the population.

g) Identify cases of rare forms of cancer that can be studied.

h) Provide data on patient survival.

i) Aid individual hospitals in their efforts at cancer control by providing data about demographic and medical characteristics of the patient population and catchment area.

There is an evident need for these kinds of information. There is no regional or statewide plan to deal with cancer in Illinois. The lack of such a plan means that the capability to effectively manage many forms of cancer which are preventable, detectable in an early stage when most amenable to treatment, or curable if treated with available state-of-the art procedures, is not uniformly available to all residents of Illinois. Moreover there is limited capability to assess and respond to unusual clusters of cases that may indicate special risks among certain segments of the population. The development of such a plan which would create this capacity requires the availability of population-based data on the cancer experience of Illinois residents.

DESCRIPTION OF THE PILOT STUDY

The East Central Region of Illinois

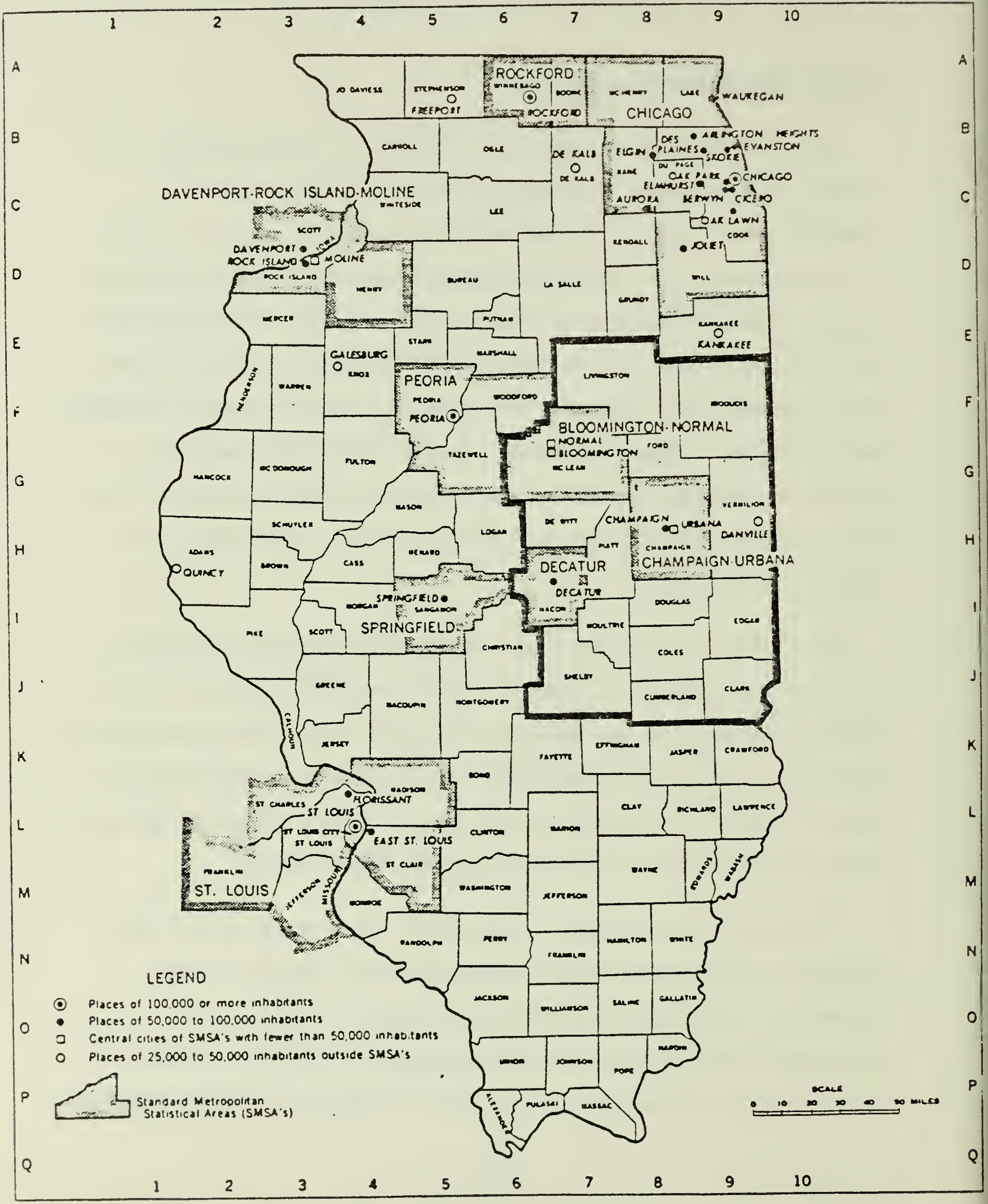
East Central Illinois comprises 16 counties and 800,000 people. It includes three mid-sized Standard Metropolitan Statistical Areas: Champaign-Urbana, which is in the center of the region, Decatur, which is in the southwestern part and Bloomington-Normal which is in the northwest. Champaign-Urbana is located 140 miles south of Chicago. It is the home of one of the two campuses of the University of Illinois. Over half of the cancer patients seen in the area are diagnosed at one of two major treatment centers located in Champaign-Urbana. These are the Carle Foundation Hospital and Clinics, and Burnham and Mercy Hospitals and Christie Clinic. Large treatment facilities are also found in Decatur, Bloomington and Danville (see figure 1).

This region selected for study has an annual incidence estimated at about 2300 cases per year. Moreover the 1970 and 1980 censuses indicate that the population in the region is stable with little in-or-out-migration. Agriculture is the primary industry but there are also manufacturing and service industries in the region. Two large employers are the University of Illinois and Illinois State University at Bloomington-Normal.

There are ten county health departments, 104 licensed nursing homes, two free-standing clinics, and 30 hospitals in East Central Illinois including a large Veterans Administration Hospital in Danville. Approximately 1000 licensed physicians practice in the region. There is a four year medical school at the University of Illinois in Urbana-Champaign.

Figure 1

EAST CENTRAL ILLINOIS
CANCER SURVEILLANCE PILOT STUDY REGION



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Three nursing schools and a four year training program in medical records administration are also located in the area.

Demographic Characteristics of the Region

The total population of the region in 1970 was 763,058 (Table 1). There was a net increase of five percent between 1970 and 1980 so the population in 1980 was 798,650. The counties in the region grew at different rates and the changes in population ranged from a seven percent loss of population in Ford County to a gain of 13 percent in Coles County. The segment of the population aged 65 and older grew more rapidly, relative to the total population of the region. Within this age segment there was a 12 percent increase compared to five percent for the whole population and the proportion of the total population over age 65 advanced from 11 to 12 percent.

Thirty seven percent of the population is rural (Table 2). Those counties with the major urban areas were Macon, Champaign, and McLean. Other counties like Iroquois and Cumberland were between 80 percent and 100 percent rural.

Cancer Data Sources

Data on cancer diagnoses are usually obtained from hospitals, physicians, discharge data services, dentists and oral pathologists, private laboratories, screening and detection programs, health insurance carriers, and death certificates. The hospitals, private laboratories, and death certificates are the primary sources of information. In considering hospitals those major referral centers outside the region of interest must be included if they treat patients who reside in the population of interest.

Table 1

NUMBER OF PERSONS, TOTAL AND 65 YEARS AND OLDER, AS WELL AS OVERALL MEDIAN AGE FOR EAST CENTRAL ILLINOIS COUNTIES: 1970 and 1980

Cancer Surveillance Pilot Study

COUNTY	TOTAL NUMBER PERSONS					NUMBER PERSONS 65 YEARS and OLDER		
			Percentage Change	Median Age				Percentage Change
	1970	1980	1970-80	1970	1980	1970	1980	1970-80
Champaign	163,281	168,392	3.0	22.8	24.5	9,739	12,059	24.0
Clark	16,216	16,913	4.0	35.4	34.4	2,766	2,938	6.0
Coles	47,815	52,260	9.0	25.5	26.1	5,455	6,398	17.0
Cumberland	9,772	11,062	13.0	32.1	30.9	1,459	1,591	9.0
DeWitt	16,975	18,108	7.0	32.7	32.2	2,422	2,569	6.0
Douglas	18,997	19,774	4.0	30.8	31.5	2,213	2,623	19.0
Edgar	21,591	21,725	2.0	34.8	33.9	3,274	3,595	10.0
Ford	16,382	15,265	-7.0	32.4	33.9	2,123	2,446	15.0
Iroquois	33,532	32,976	-2.0	31.5	33.0	4,408	5,073	15.0
Livingston	40,690	41,381	2.0	29.1	20.6	5,308	5,711	8.0
Macon	125,010	131,375	5.0	28.7	30.1	13,465	15,324	14.0
McLean	104,389	119,147	10.0	24.7	26.1	10,498	11,554	10.0
Moultrie	13,263	14,546	10.0	33.1	32.9	2,075	2,367	14.0
Piatt	15,509	16,581	7.0	31.0	31.7	1,909	2,056	8.0
Shelby	22,589	23,923	6.0	32.6	32.7	3,407	3,747	10.0
Vermillion	97,047	95,222	-2.0	30.9	31.2	11,830	12,471	5.0
Total (16 counties)	763,058	798,650	5.0			82,351	92,522	12.0

Source: U.S. Census, 1970 and 1980.

Table 2

SELECTED CHARACTERISTICS FOR RURAL PORTIONS OF COUNTIES IN EAST CENTRAL ILLINOIS: 1980

Cancer Surveillance Pilot Study

County	No. Persons	%	Median Age
Champaign	38,953	23	28.9
Clark	10,251	61	32.3
Coles	13,850	26	29.6
Cumberland	11,043	100	30.9
DeWitt	10,094	56	32.0
Douglas	10,514	53	31.7
Edgar	11,840	54	33.4
Ford	7,509	49	33.8
Iroquois	27,433	83	32.5
Livingston	22,416	54	30.8
Macon	23,511	18	29.8
McLean	33,882	28	30.5
Moultrie	10,020	69	32.3
Piatt	11,828	71	30.6
Shelby	18,664	78	32.1
Vermilion	32,348	34	30.7
Total	294,156	37%	

Source: U.S. Census, 1980

Of the 30 hospitals in the study region 26 have medical-surgical facilities that diagnose cancer and were eligible to participate. These hospitals had a total of 4,852 beds and varied in size from 23 beds to 963 beds in 1981 when the project was initiated. Eleven had operational cancer registries and six of these were approved by the American College of Surgeons (Table 3). Within the hospital there are a variety of sources that can be used for case ascertainment. These include medical records and tumor registries, pathology departments, radiology and radiotherapy, outpatient records, and records from specialized services like pediatrics, hematology, and dermatology. In this study it was found that the primary sources of data were the medical records and the tumor registries.

Recruitment Procedures

Before the pilot study was initiated, interviews were sought with the newspapers and television stations in the region. This policy promoted interest in the area for the project. It was adopted following publication of a series of articles in the Commercial News of Danville, Illinois in Vermilion County which called attention to what appeared to be a disproportionately high mortality rate due to cancer in that county. It was subsequently shown that there were errors in the calculation of the mortality rates. When these were corrected the residents of Vermilion County were shown to be at no greater risk than residents in other counties in the region. However, the episode illuminated the very high interest among the population in the area and the need for accurate data. It is of particular interest that by the end of the study Vermilion County was the only county where there was strong voluntary support for the project and 100 percent participation by the hospitals.

Table 3

HOSPITALS IN EAST CENTRAL ILLINOIS ELIGIBLE TO PARTICIPATE IN THE CANCER SURVEILLANCE PILOT STUDY

Name of the Facility	No. of Beds[1]	No. of Annual Admissions[1]	County	Participation Status[2]	
				1982	1983
+*Burnham Hospital	214	9,450	Champaign		
+*Carle Foundation Hospital	283	12,487	"	x	x
Cole Hospital	65	-	"		
+*Mercy Hospital	266	9,915	"		
+U.S. Air Force Hospital	55	-	"	x	x
Sarah Bush Lincoln Health Center	197	8,738	Coles		
+Dr. John Warner Hospital	52	1,999	DeWitt	x	x
Douglas County Jarman Memorial Hospital	43	1,397	Douglas		
Paris Community Hospital	98	2,424	Edgar	x	x
Gibson Community Hospital	85	1,703	Ford		
Paxton Community Hospital	30	828	"	x	x
Central Community Hospital	33	692	Iroquois	x	x
Iroquois Memorial Hospital	133	2,506	"		
Fairbury Hospital	117	1,891	Livingston		
+St. James Hospital	118	3,797	"		
+*Decatur Memorial Hospital	393	14,332	Macon	x	
St. Mary's Hospital	402	16,260	"		
Brokaw Hospital	249	7,339	McLean		
Mennonite Hospital	230	6,438	"		
+St. Joseph's Hospital Medical Center	180	8,308	"		
John and Mary Kirby Hospital	22	583	Piatt	x	x
Shelby Memorial Hospital	74	1,974	Shelby	x	x
Hoopeston Community Memorial Hospital	94	1,544	Vermilion	x	x
+*Lakeview Medical Center	221	11,642	"	x	x
+*St. Elizabeth's Hospital	235	10,670	"	x	x
+Veterans' Administration Medical Center	963	4,570	"	x	
Total Beds	4,852				

*Hospitals with an American College of Surgeons approved Cancer Program/Registry.

+Participate in the American Cancer Society Cancer Incidence and End Results studies.

[1] Source: American Hospital Association Guide to the Health Care Field, 1982 Edition.

[2] Participated in the Cancer Surveillance Study x.

The first formal contact regarding the study was made between officials from the Illinois Department of Public Health and the hospital administrators. This contact was in the form of a letter introducing the project coordinator, Dr. Alexander. Following this letter Dr. Alexander wrote to each administrator and with her letter included a packet of materials describing the study and its objectives, the Illinois Cancer Council, and the need for a population-based registry in Illinois. The letter also requested an appointment at which Dr. Alexander would describe the project in more detail and solicit their participation. All but two administrators agreed to the meeting.

After this initial contact with the hospital administrators, efforts were made to inform the physicians in the region about the study and the proposed voluntary registry. This effort was carried out by Dr. Alexander, who visited regular staff meetings, participated in tumor conferences at all regional hospitals and spoke at county medical society meetings when invited. The response by physicians whom she was able to reach was generally positive and in some cases very enthusiastic. Eventually, about one-third of the physicians in the region had heard about the proposed registry through these meetings.

Efforts were also made to inform tumor registrars in the region. As part of the program, training workshops were organized for registrars at participating hospitals. An initial training workshop was given in Champaign on April 8, 1982. Medical record department directors, tumor registrars, administrators and some physicians attended. In addition, registrars were given further "hands-on" training by abstracting test charts. Supplemental training was carried out by mail using self-testing answer sheets. Following the workshop several hospitals that originally planned to do their own abstracting requested that the ICC do it for them. These hospitals saw few cancer patients and reasoned that abstractors in the hospital would not do enough cases to maintain their efficiency with the procedures specified for the study. In addition one of the larger facilities in the region that saw many cancer patients requested that the ICC abstractor do all their records.

During the first year, while the registry was being developed, case-finding techniques and the structure of relevant records at each hospital were reviewed on-site by Dr. Alexander, the project manager and/or the abstractor. While at the hospitals initial problems with abstracts were reviewed with hospital staff, particularly at those hospitals where the ICC abstractor was not abstracting from the medical records and tumor registry. Through the two years the the project manager or the abstractor periodically visited the participating hospitals to maintain liaison and to answer questions as they arose. In addition the tumor registrar/quality control manager for the project and her assistant gave special assistance to the registries when needed by telephone.

Participation and Reasons for Refusal

By September, 1982 eleven hospitals had agreed to participate. By the following January two additional hospitals agreed and the total that eventually participated remained at thirteen. These hospitals represented about 50 percent of the beds in the region and we project that they saw about two thirds of the cancers. However, because only one half of the hospitals in the region voluntarily participated in the registry program a population-based system was not established (Table 3).

There are several reasons for this high refusal rate within the region. Some of these reasons are probably unique to the region or to the particular situation, while others would be likely to arise wherever cancer has not been made legally reportable, since they relate to the hospitals' liability for disclosing confidential information and to the costs to the hospital when such programs are initiated.

Confidentiality and Liability

Several hospitals were concerned about the confidentiality of the information they were asked to provide. Although the Director of IDPH declared the project a medical study under the state's Medical Studies Act, this was not viewed by some hospitals as adequate protection. The Illinois Medical Studies Act provides protection to institutions who provide confidential information to the state or to an agency acting as an agent for the state. In addition it protects such information from forced disclosure. Additionally, the ICC executed an agreement with each participating hospital limiting the staff at ICC who could access the data and providing for return or destruction of all confidential materials at the conclusion of the study. In spite of these measures some hospitals remained uncomfortable with the issue.

Cost

Some hospitals were also reluctant because of the costs of participation. Although all major costs were underwritten by DENR and IDPH, some residual costs associated with the study remained. All direct costs associated with abstracting or copying the records and the postage for sending data to the ICC were paid by the study. Costs associated with case-finding including the costs of pulling each record and refiling the charts were paid by the institution. Although these costs were estimated to be minimal they were not judged insignificant by some of the hospitals.

Duplication of Effort

Many of the hospitals in the region were participating in on-going studies of incidence and survival being carried out by the American Cancer Society (ACS), Illinois Division. Although the pilot study had different objectives that in fact complemented those of the ACS, several hospitals felt that the dual burden was excessive. Some also felt that the American College of Surgeons--Commission on Cancer was obtaining data and that the pilot study also overlapped with those efforts. It is hard to say whether this argument was unique to this region or would be advanced in other areas as well; it was an ever present issue.

The Temporary Nature of the Project

Closely related to the concerns about duplication of efforts were complaints that the DENR/IDPH project was for a limited time period and not a permanent state program. Some hospitals were reluctant to expend the time and effort necessary to participate in a two year program.

Conclusions

For all the reasons noted above, it became clear over the course of the study that a voluntary system is not workable if the objective is to obtain reliable, population-based data on the cancer experience in Illinois. Legislation mandating that hospitals report all malignant and in situ conditions is necessary and must address the issues raised by those who declined to participate.

Specifically, legislation must explicitly protect the confidentiality of the data. It must expressly indicate that the data will become state property and be protected under the laws of Illinois governing handling of confidential materials. Second, the legislation must provide reimbursement to participating hospitals or provide staff to carry out all necessary functions. If the hospitals are required by law to report all malignant neoplasms, then the hospitals will have a legitimate reason to pass some of the costs related to registration on to patients and insurers. This will promote their cooperation. Legislation will legitimate the registry and enable the state to negotiate with out-of-state providers such as the Mayo Clinic to provide data on Illinois residents diagnosed and/or treated there. (The Mayo Clinic will only release such information if a state law requiring reportability exists). Legislation making cancer reportable will also insure the permanence of the registry and will alleviate concerns by hospitals that their efforts in responding to the request for their data will not be wasted. Moreover, if cancer reporting is mandatory then the state will not have to compete with privately sponsored programs to obtain data necessary to protect the public health in Illinois.

A review of the experience of other states indicates that a statute making cancer a reportable disease and/or a health department regulation requiring that new diagnoses be reported is necessary to assure 100 percent participation by all eligible to report. It goes without saying that such a requirement only provides a legal framework and sense of program stability. Ultimately the hospitals must be persuaded of the importance of the program and must be willing to cooperate with the state. In the absence of such education and cooperation the registry will not be completely successful.

ORGANIZATION OF THE REGISTRY

The Dataset

The primary objective of this pilot study was to obtain data on newly-diagnosed cases which could be used to compute an incidence rate for the region. No effort was made to obtain any follow-up data on the status of cases after diagnosis. Follow-up data are necessary for calculating survival rates; however, in a two year project no meaningful survival data could be collected.

The dataset selected for this study was modeled after that used by a national network of 21 comprehensive cancer centers in which the ICC participates. It is a minimal dataset containing items judged by epidemiologists to be most important in identifying cases for more detailed studies. The dataset selected is compatible with but not as extensive as the SEER dataset. Finally, to enhance the relevance of the program to local participating hospitals, compatibility with the requirements of the American College of Surgeons--Commission on Cancer, was emphasized.

The actual data items are summarized in Table 4. Section A in the table contains items necessary to uniquely identify the patient. These are confidential items that identify both the patient and the reporting institution and are absolutely essential for administering the registry. Without them there is no way to identify duplicate registrations or to follow-up patients after initial treatment. This information is also important for research purposes; without it record linkage could not be established.

Section B in Table 4 contains demographic and life style items. These items are not uniformly available in the hospital-based tumor registry or

Table 4

LIST OF DATA ELEMENTS ABSTRACTED FROM CANCER PATIENT RECORDS

EAST CENTRAL ILLINOIS CANCER SURVEILLANCE PILOT STUDY

Section A: Patient Identification
- Operation
- Originating Institution
- Accession Number
- Sequence Number
- Date of Birth
- Patient Name

Section B: Demographic and Life Style Data
- Residence
  - *State
  - Zipcode
  - *County
- Sex
- Race
- Ethnicity
- Birthplace
- Primary Occupation/Industry
- Tobacco Use
- Alcohol Use

Section C: Prior History
- Previous Cancer-Directed Treatment
  - Surgery
  - Radiation Therapy
  - Chemotherapy
  - Endocrine
  - Immunotherapy
  - Other Cancer Therapy

Section D: Referral
- Attending Physician

Section E: Diagnosis
- Date of First Contact
- Primary Site
- Class of Case
- Date of Initial Diagnosis
- Method of Best Confirmation of Diagnosis
- Basis of Diagnosis/Morphology
  - Histology
  - Behavior
  - Grade

Section F: Extent of Disease
- Stage (ICC) at First Contact
- Stage (Other Method)

Section G: Treatment Since First Contact
- Cancer-Directed Treatment
  - Surgery
  - Radiation Therapy
  - Chemotherapy
  - Endocrine Therapy
  - Immunotherapy
  - Other Cancer Therapy
- Date Treatment Began

Section H: Patient Status
- Followup
  - Date of Last Contact
  - Patient Status
  - Disease Status
  - Laterality
  - Quality of Survival
  - Autopsy
  - Cause of Death (Cancer Related)

Section I: Remarks
- Abstracted by
- Date Abstracted

*Codes assigned at ICC.

medical record. When they are not available in either they usually cannot be obtained. These items are primarily used to carry out descriptive epidemiologic studies and to identify potential exposures that might be the basis for more detailed, analytic studies which could require patient interviews. The first four items on the list are generally available and can be accessed from the medical record face sheet in most instances. Place of birth is more uncertain and is typically not in the hospital-based tumor registry although it may be in the medical record. The life style factors: primary occupation/industry and tobacco and alcohol use are not usually available from the tumor registry unless they are somehow believed to be directly implicated in the tumor. Sometimes they are available in the medical record but even this is uneven as we will discuss below in the section on "Quality Control".

The prior history items in section C of the table refer to all cancer-directed treatment received by the patient for the reported cancer before first contact with the reporting hospital. These items are used primarily to distinguish new cases from prevalent cases in the community. Cases that have a history of prior treatment would not be included in computation of incidence unless their most current cancer was a newly-diagnosed tumor, unrelated to their prior history.

Information on referral and the attending physician (Section D) is another of the confidential items in the registry used for internal administration of the dataset. Physician's identity is used primarily to obtain permission to contact cases for study. Such information might also be used to study patterns of referral for studies of care delivery in Illinois.

The most important disease-related information is in sections E and F. Included in section E are the dates of first diagnosis and contact with the registry, the primary site of the tumor, the class of the case (diagnosis, treatment or subsequent care), the method by which the diagnosis was confirmed and the basis for the diagnosis including the histology, behavior, and grade of the tumor. Section F contains information about the extent of disease or stage at diagnosis. This information includes whether the tumor was localized, regional, or had metastasized.

Section G summarizes the treatment received for the current tumor at the reporting facility. In the coding scheme used each form of treatment was simply coded as to whether it was used or not. The sequence was not recorded.

In section H, the patient's last known vital status and some basic data on the patient's condition when last contacted are recorded. The most important data elements are the date of last contact and whether the patient was alive at that contact. Laterality is of interest for cancers of paired organs such as breast, ovary and testis because such patients are at risk for a second primary tumor in the other organ in the pair.

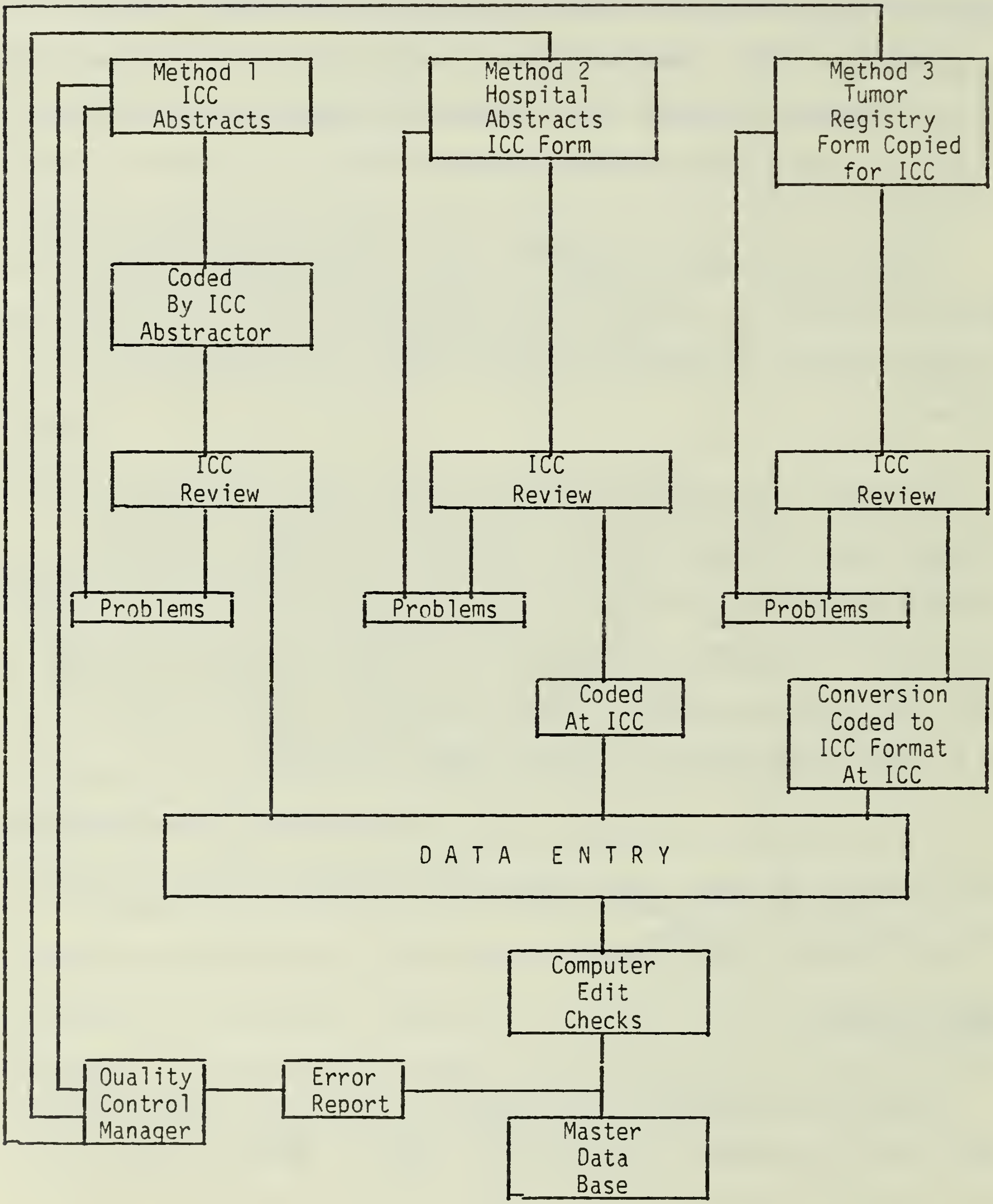
Finally, section I of the table contains information about who obtained the information and when. This is important information for quality control and for abstractor education.

Data Collection

Participating hospitals were permitted to report their cancer patient data in one of three ways (see Figure 2). Method 1, chosen by eight of the

Figure 2

CANCER DATA FLOW CHART
CANCER SURVEILLANCE PILOT STUDY



thirteen participants, required hospitals to report each new case to the ICC abstractor who then went to the hospital and abstracted the necessary data from the records. Two hospitals chose method 2, in which the hospital registrar abstracted the case data using the ICC forms. Method 3, chosen by three hospitals, required that the hospital send photocopies of the patient's tumor registry abstract to the quality control manager at the ICC who abstracted the data from the form and entered it into the registry data file.

Personnel at hospitals that chose method 1 completed a Confidential Information Report form when a patient was initially diagnosed. The hospital retained a copy of this form and sent the original to the ICC field abstractor in Champaign. When sufficient cases were accrued to allow a full day of work at that hospital the abstractor contacted the hospital's director of medical records to arrange to have the records pulled for abstracting. The abstractor would leave copies of the completed forms if the hospital requested them.

Hospitals that chose method 2 did their own case finding and abstracting from patient records using ICC forms. The ICC abstractor assisted the personnel at these hospitals and thoroughly trained them in the ICC abstracting procedures. She was also available to answer questions as they arose. Completed forms were sent in batches to the ICC where they were reviewed and coded for entry onto the computer. This method was necessary for the Veterans Administration Hospital because federal regulations prohibit access to records by anyone not employed by the VA. However, the required consent procedures were quite cumbersome and the method was not completely satisfactory. It should be recalled that several other hospitals initially chose this method but after the training sessions elected to have the ICC abstractor come and obtain the data from their records.

Three hospitals chose method 3. They identified cases, photocopied the registry data abstracts and sent them to the ICC for coding and data entry. These hospitals used their own forms; their information required conversion to the ICC format before coding and data entry could be carried out. This procedure created several problems and delays which ultimately caused delay of the preparation of the final report on 1982 data. In addition the level of case ascertainment was variable. In one hospital it was excellent, due to the efforts of the individual registrar. At another hospital, however, the majority of cases that were seen were not reported to the ICC in time to be included in the report sent to that hospital. The missing cases were eventually identified, sent to the ICC, coded and entered. Data were included in the quality control analysis.

Data Quality

Quality control is important to insure that the data in the registry are reliable, complete, consistent and comparable. In this pilot study several different quality control measures were incorporated into the system. First, before any data were abstracted a Data Acquisition Manual was prepared defining each item and explaining how these items were to be abstracted and coded from the medical record.

The Data Acquisition Manual was used to train the ICC field abstractor and the abstractors at the hospitals that elected to do their own abstracting. As we have noted this training was supplemented with exercises in abstracting that were completed at home by the abstractors as part of the training process. These test cases were evaluated by the director of quality control at the ICC.

However the data were obtained from the registries, in all cases they were centrally reviewed and coded at the ICC where the final analyses and other checks on the data were carried out. Two forms of quality control were initiated after the data were received. These were a manual review of the abstract before data entry and a series of computerized error checks.

The manual review of the abstracts was carried out to determine the accuracy of coding of items for which computerized checks could not be carried out. In general this phase of the review required judgments by someone knowledgable about types of cancers and appropriate management and it relied on data that was not computerized, usually written documentation obtained from the medical record. The checks that required manual review generally involved assurance that: the treatment recorded was appropriate for the type or site of the tumor; the stage recorded in the abstract agreed with written documentation; and site and histology were correctly coded based on written documentation. Abstracts with apparent discrepancies were not entered into the system until the data were rechecked at the submitting institution and errors were corrected.

An important aspect of operating a registry of this size is the ability to manage the data by computer. Since data management in this project relied primarily on the computer for data quality control the computer arrangements will be discussed here.

The ICC used a DEC PDP 11/70 computer for the data management activities on this project. However, any micro or mini computer with sufficient memory and appropriate software could be used. Data entry and quality control required a full range of data management functions including: data entry, internal editing for legal codes and consistency between data items, dictionary development, updating, and retrieval of data for manipulation and preparation of reports. In this section we will only consider those aspects of data processing related to data entry and quality control.

The system of software that was employed was based upon a menu-driven system that enables the user to:

1) prepare screens to enter and up-date data;

2) create and compile a data dictionary that defines each item and provides a set of commands that defines legal code values and inter-item consistency necessary to clean the data;

3) sort and join files on the basis of several data items;

4) print selected values in a table;

5) produce multidimensional cross-tabulations.

The first task undertaken for quality control was the preparation of a data dictionary which defined each item based on the values in the Data Acquisition Manual and the form by which it was to be entered into the dataset. Within the dictionary, each item was given a name, assigned a type (either numeric or character string), assigned a field length, assigned a label (e.g., date of birth), assigned a legitimate range of values (e.g., age greater than 00 years and less than 100). In addition inter-item specifications were written to insure that impossible combinations were rejected (e.g. a female with prostate cancer) or that proper combinations were entered (e.g. appropriate site/histology combinations).

After the ICC tumor registrar/quality control manager conducted the manual review, data were entered into the computer. Using the data dictionary the computer produced a facsimile of the data abstract form on the screen. Data were then entered into the computer on this form. By using this technique errors were substantially reduced.

After the data were entered a program was run through the data dictionary to identify incorrect values and note and correct inconsistencies between items. The computer would then print out erroneous items for correction. In some cases the errors were the result of data entry in which case comparison with the abstract held at the ICC was sufficient to correct the error. In other instances the error was in abstracting. In these cases the field abstractor reviewed the medical record a second time. This process was repeated for all data entered into the database.

As three methods of data collection strategies were used in this project (Figure 2), we were interested in determining which of these methods provided the most information of the best quality. One measure of quality is the use of codes for unknown and ill-defined data. A sample of data items that were coded in this way was reviewed, grouped by size of the hospital and by whether the data were abstracted at the hospital, making use of all sources of information, or at the ICC where only the registry abstract was available. Of the two hospitals that elected to use their own abstractor, only one did so consistently. Data from this hospital was reviewed with the abstractor-coded data. The other hospital submitted only a small percentage of cases and was not included in this review.

First the general availability of the items will be considered. In general it appears that patient-related items (e.g., occupation, tobacco and alcohol use, quality of survival) were frequently unavailable from any source consulted. In contrast, disease-related items (e.g., site, histology, treatment modality) were more consistently available. One exception among the disease-related items was the histology grade (degree of cell differentiation) which was missing in almost half the cases regardless of the source of information. In general these differences in item availablity hold regardless of bed size of the hospital or source of data. However, there were further differences when these latter factors were considered.

There were 1,089 cases coded directly by the abstractor at the hospitals and 1,108 cases recoded at the ICC from registry materials. Unknown codes occurred less frequently in the data abstracted directly at the hospital than in the data recoded at the ICC. Items such as birthplace, tobacco use, alcohol use, current radiation and chemotherapy, quality of survival, and cause of death were all more likely to be coded as unknown if the data were recoded at the ICC from registry materials. The differences, shown in Table 5, suggest that the information is in the medical record but is not abstracted by the registry. Thus, the abstractor can obtain the data from the medical record if the abstracting is being done in the field. When it is done from a photocopy of the registry in a central location other sources are not available and either the hospital has to be recontacted and

Table 5

USE OF UNKNOWN AND ILL-DEFINED CODES BY SOURCE OF CODING

EAST CENTRAL ILLINOIS CANCER SURVEILLANCE PILOT STUDY

Data Elements	By Abstractor		By Recoding	
	Frequency	%	Frequency	%
Section B: Demographic and Life Style				
Birthplace	114	10.5	804	72.6
Occupation	605	55.6	605	54.6
Industry	576	52.9	589	53.2
Tobacco Use	407	37.4	683	61.6
Alcohol Use	473	43.4	811	73.2
Section E: Diagnosis				
Primary Site (Ill-defined)	3	0.3	1	0.9
Primary Site (Unknown)	26	2.4	33	3.0
Basis of Diagnosis				
Histology (Unknown)	3	0.3	11	1.0
Histology (Ill-defined)	10	0.9	17	1.5
Grade	524	48.1	514	46.4
Section F: Extent of Disease				
Regional Stage	12	1.1	26	2.3
Nonlocal Stage	1	0.1	0	0.0
Unstaged	140	12.9	152	13.7
Section G: Cancer-directed Treatment Since First Contact				
Surgery	1	0.1	4	0.4
Radiation Therapy	4	0.4	22	2.0
Chemotherapy	3	0.3	25	2.3
Endocrine	0	0.0	1	0.1
Immunotherapy	0	0.0	0	0.0
Other	0	0.0	0	0.0
Section H: Status				
Disease Status	512	47.0	390	35.1
Quality of Survival	572	52.5	1064	96.1
Cause of Death	32	2.9	62	5.6

NOTE: Data based on a review of 1,089 cases coded by the ICC abstractor and 1,108 cases recoded at the ICC.

requested to check the medical record or the item is coded as either missing or incomplete.

Moreover, the general differences in availability of patient data and disease data are magnified when the differences in method of collection are examined. Thus, tobacco use was listed as unknown in 37 percent of the abstractor coded cases and in 62 percent of the recoded data; alcohol use was unknown in 43 percent of the abstracted data and 73 percent of that which was recoded; and quality of survival was unknown in 52 percent of the abstracted data and 96 percent of the recoded data. Disease-related data showed very small differences attributable to either the abstracting or recoding methods.

Two hundred thirty cases were submitted from hospitals with less than 100 beds (8 hospitals) and 1967 cases from hospitals with more than 100 beds (4 hospitals) (see Table 6). In general there were few differences due to hospital size; however, some of those that were found are of interest. First, the biggest difference due to size was related to availability of information on stage of disease; 22 percent of cases in hospitals with 100 or fewer beds were unstaged compared with 12 percent in those with more than 100 beds. On the other hand disease status was unknown in 25 percent of the hospitals with 100 or fewer beds but was unknown in 43 percent of those with more than 100 beds. Similarly, 51 percent of the hospitals with 100 beds or less did not record the quality of survival compared with 77 percent of those with more than 100 beds. Those with 100 or fewer beds were also slightly more likely to report the extent of radiation therapy and chemotherapy than larger hospitals. In general it would seem that larger

TABLE 6

USE OF ILL-DEFINED AND UNKNOWN CODES BY HOSPITAL SIZE

Data Elements	From Hospitals 100 Beds or Less		From Hospitals Over 100 Beds	
	Frequency	%	Frequency	%
Section B: Demographic and Life Style				
Birthplace	91	39.6	827	42.0
Occupation	137	59.6	1073	54.5
Industry	123	53.5	1042	53.0
Tobacco Use	119	51.7	971	49.4
Alcohol Use	136	59.1	1148	58.4
Section E: Diagnosis				
Primary Site (Ill-defined)	2	0.9	2	0.1
Primary Site (Unknown)	5	2.2	54	2.7
Basis of Diagnosis				
Histology (Unknown)	2	0.9	12	0.6
Histology (Ill-defined)	7	3.0	20	1.0
Grade	127	55.2	912	46.3
Section F: Extent of Disease				
Regional Stage	0	0.0	38	1.9
Nonlocal Stage	0	0.0	1	0.1
Unstaged	50	21.7	242	12.3
Section G: Cancer-directed Treatment Since First Contact				
Surgery	1	0.4	4	0.2
Radiation Therapy	3	1.3	23	1.2
Chemotherapy	2	0.9	25	1.3
Endocrine	0	0.0	1	0.1
Immunotherapy	0	0.0	0	0.0
Other	0	0.0	0	0.0
Section H: Status				
Disease Status	58	25.2	844	42.9
Quality of Survival	117	50.9	1519	77.2
Cause of Death	8	3.5	86	4.4

NOTE: Data based on a review of 230 cases from hospitals with 100 beds or less, and 1967 cases from hospitals with over 100 beds.

hospitals are less likely to record information about procedures that are likely to be provided on an out-patient basis than smaller hospitals and are also considerably less likely to have data on the patient's status after discharge.

Another indication of quality is the extent to which cases of cancer treated in the hospital are not registered in the tumor registry. A case-finding audit was completed in 1982. The ICC abstractor reviewed sources of cases in six hospitals that did not have existing tumor registries. Initially 173 cases were reported by the hospital personnel; an additional five cases were found by audit. No new cases were found in three hospitals; in two hospitals one case each was found, and in a third one three cases were discovered. A casefinding audit was not carried out at any hospital with a registry but in a statewide registry this procedure should be carried out randomly on all hospitals in the system and a specified percentage should be set as a quality standard. Hospitals exceeding that percentage should be offered additional training and assistance for their registry staff. Hospitals with poor records in the audit should be reaudited more frequently.

ANALYSIS OF PATIENT DATA, 1982

Table 7 contains the distribution of patients seen at the participating hospitals in the East Central Illinois Surveillance Pilot Study. Column one in the table contains an aggregate count of all patients reported by all participants; column two contains a unduplicated count in which the patients seen at more than one hospital were counted only at the first hospital. A comparison was made between the data obtained from the ECI registry with SEER data from Iowa, 1973-1976 which indicates that the two distributions are similar. The Iowa data contain 3 percent more colon cancers than were found in the ECI region. In contrast Iowa reported a smaller percentages of cancers of the lung (12 percent vs. 16 percent) and fewer female breast cancers (13 percent compared with 16 percent).

These data also indicate the importance of obtaining identifying information on patients diagnosed in the area. The unduplicated number of cases is 1,886 compared with the 2,264 total. Thus 378 cases were treated in more than one hospital or treated in the same hospital more than once which is almost 20 percent or one in five cases. If duplicate cases were not excluded the incidence of cancer would appear to be greater than it actually was. The unduplicated data are still misleading regarding incidence in the region since not all hospitals reported to the registry (i.e. it is not population-based). More problematic, however, several participating hospitals did not report all their cases. This under-reporting was discovered during the review of the data in preparation for the 1982 reports to the individual institutions.

Table 7

DISTRIBUTION OF CANCER PATIENTS DIAGNOSED AND/OR TREATED BY SITE

EAST CENTRAL ILLINOIS (ECI) CANCER SURVEILLANCE PILOT STUDY

	Duplicated (2)		Unduplicated (3)	
Buccal Cav. & Pharynx (1)	79	(3.5)	68	(3.6)
Esophagus	15	(0.7)	14	(0.7)
Stomach	50	(2.2)	47	(2.5)
Small Intestine	3	(0.1)	2	(0.1)
Colon	181	(8.0)	154	(8.2)
Rectum	114	(5.0)	93	(4.9)
Pancreas	28	(1.2)	26	(1.4)
Other Digestive Org. (1)	32	(1.4)	27	(1.4)
Lung	349	(15.4)	286	(15.2)
Other Respiratory Sys. (1)	41	(1.8)	35	(1.9)
Bones & Joints	2	(0.1)	1	(0.1)
Soft Tissues & Heart (1)	15	(0.7)	13	(0.7)
Melanomas, Skin	33	(1.5)	24	(1.3)
Other Skin	3	(0.1)	2	(0.1)
Breast, Female	338	(14.9)	247	(13.1)
Breast, Male	1	(0.0)	1	(0.1)
Cervix	126	(5.6)	114	(6.0)
Corpus	74	(3.3)	67	(3.6)
Ovary	52	(2.3)	47	(2.5)
Other Female Genital (1)	20	(0.9)	15	(0.8)
Prostate	225	(9.9)	183	(9.7)
Other Male Genital (1)	18	(0.8)	17	(0.9)
Urinary Bladder	116	(5.1)	100	(5.3)
Kidney, Renal Pelvis	40	(1.8)	35	(1.9)
Other Urinary Organs (1)	3	(0.1)	3	(0.2)
Eye and Orbit	1	(0.0)	1	(0.1)
Brain and Nerv. Sys. (1)	37	(1.6)	33	(0.7)
Thyroid	17	(0.8)	14	(0.7)
Endocrine System (1)	6	(0.3)	6	(0.3)
Non-Hodgkins Lymph.	70	(3.1)	63	(3.3)
Hodgkins Lymphoma	28	(1.2)	24	(1.3)
Multiple Myeloma	43	(1.9)	36	(1.9)
Leukemia, Nos	6	(0.3)	3	(0.2)
Leukemia, Acute	14	(0.6)	12	(0.6)
Leukemia, Chronic	18	(0.8)	15	(0.8)
Other Hematopoietic (1)	0	(0.0)	0	(0.0)
Unknown & Ill-defined (1)	66	(2.9)	58	(3.1)
Total	2264	(100.0)	1886	(100.0)

(1) SEER Site Groupings
Sites Coded from International Classification of Diseases for Oncology (ICD-O), 1976 Version.

(2) Totals for 13 Participating Institutions in East Central Illinois (ECI)
Patient is counted more than once if seen at more than one institution

(3) Patients seen at more than one institution counted only once

Dataset

In our selection of the dataset for this project several criteria were used. First, a minimal dataset sufficient to identify patients for epidemiological research was essential. Second, we attempted to be consistent with the SEER dataset. Third, we sought consistency with the American College of Surgeons dataset. Based on our experience with the availability of data in the ECI registry, we would recommend that the dataset for a statewide registry contain fewer items. Specifically we suggest the following:

-Section B: Delete primary occupation/industry, alcohol and tobacco use;

-Section C: Delete completely and simply record whether the patient was treated previously for the cancer;

-Section G: Delete all (current cancer treatment);

-Section H: Delete all (patient and disease status).

Deletion of Section H removes the follow-up data from the registry. This is recommended as a cost savings. Passive follow-up in which the registry data is linked with death certificate information should be used for determining current patient status. An annual search of the National Death Index should also be done to insure that out-of-state deaths are recorded.

Organization of a Registry

Location: Assuming a statewide registry is mandated by a law making cancer a reportable disease, it should be located in Springfield and operated under the auspices of the Illinois Department of Public Health. Regional field offices should be established and located in regional offices of the IDPH.

Advisory Board: An advisory board should be established including representatives from: the Illinois Departments of Energy and Natural Resources and Public Health, the Illinois Hospital Association, the Chicago Hospital Council, the Illinois State Medical Society, the Chicago Medical Society, the University of Illinois School of Public Health, the Governor's Advisory Committee on Cancer Control, the Chicago Board of Health, and the Illinois Cancer Council. In addition hospitals throughout the state should be invited to nominate representatives from their cancer committees or medical directors of their registries. Five or six of these should be elected by the hospitals to represent their interests on this board.

An important function of the registry will be research. This board should have the power to review potential studies that propose to make use of this registry and to approve or disapprove its use for the proposed studies. Clearance from this board would be required before any grant proposal involving registry data could be submitted to a funding agency.

Data Collection: At the outset of this study we favored a decentralized approach to data collection and abstracting. Where individual hospitals had high quality data abstracting and American College of Surgeons approved tumor registries in place we did not wish to introduce duplication. However, our experience with the ECI registry suggests that the highest quality data results when an abstractor trained and supervised by the registry is responsible for the abstracting.

Personnel at hospitals that prefer to abstract their own data will require careful training and special quality control procedures. Permitting this approach is not likely to result in any measurable savings to the registry program and may adversely affect the data quality. Under no circumstances should the third method, allowing a hospital registry to reproduce its tumor abstract and send it to the Central office, be employed. This method produced very poor quality data in the pilot study.

Training and Recruitment: Before the program is initiated a Data Acquisition Manual should be prepared. This manual should contain the definitions of all items and the specific instructions for abstracting and coding them. This manual should be reviewed and approved by the advisory board to the registry before it is finalized.

Once items are selected and the manual is prepared abstractors should be hired and trained using the Data Acquisition Manual. The instruction program should include self-study using the manual; an overview of the diagnosis and treatment of cancer; classroom training in registry operations including confidentiality procedures, casefinding, abstracting and coding; procedures for identifying and coding multiple primary cancers; and "hands on" classroom experience by abstracting and coding mock patient records. Because the registry operation will be statewide, recruitment and training will have to be carried out regionally and there will have to be a regional supervisor in each regional office.

After data collection is underway regular meetings should be held with the abstractors to discuss problems encountered in the field, review quality control findings and discuss special studies that might be initiated.

Casefinding: Casefinding procedures are particularly important in establishing a population-based registry. As noted in the introduction to this report we estimate that about 44,000 new cancers will be diagnosed among members of the Illinois population each year. Most of these will be diagnosed in Illinois hospitals but care must be taken to establish contact with major treatment centers in Indiana, Missouri, and Wisconsin and with such nationally recognized cancer treatment centers as the Mayo Clinic, Memorial Sloan Kettering, M.D. Anderson, and St. Judes Children's Hospital in Memphis, Tennessee where patients may seek treatment for special cancers.

Case ascertainment procedures must be uniformly established for all hospitals and should include regular review of pathology, cytology, radiology, surgical reports and the Disease and Operations Index maintained by the medical records department. The local case ascertainment procedures at each hospital should be reviewed by the regional registry staff to ensure that all eligible cases are ascertained. Once a core ascertainment protocol is established then periodic reviews should be conducted at each location to assure the procedures are followed consistently.

At the present time the Illinois Department of Public Health in collaboration with the Illinois Hospital Association (IHA) and the Illinois Cancer Council is conducting a special study with six hospitals that participated in the ECI pilot registry to assess whether the hospital discharge data system being developed by the IHA can be used as the primary case ascertainment mechanism. As part of this study, 1982 cases reported by the registries of these hospitals are being compared against the 1982 cancer-related hospital discharge data. If using discharge data proves feasible, then reporting can be carried out by supplementing discharge data with cancer-specific information obtained from each registry. This system if implemented may allow a much reduced data set since data on many items in the system cannot be obtained from discharge data. These supplemental data would then be collected only if needed for special studies.

Data Abstracting and Coding: A data collection protocol will have to be initiated at each participating hospital. This will include case-finding procedures, procedures for obtaining records for abstraction, confidentiality requirement of the hospitals, and a schedule for abstracting that is convenient for hospital staff and appropriate for the anticipated case load of patients.

However a case is identified, before the data are abstracted, the case should be checked against the master registry file at the IDPH to see if the patient has already been identified either at that institution or at another in the state. If the case is already known then the information will be retained for followup. If it is a new case, the medical record will be requested and the data abstracted.

Abstracting and coding should be done in one step by the abstractor. However, as the quality control data from the present study show, it is very important that the abstractor have access to both the medical record and the tumor registry abstract. Experience with the pilot study indicates that the tumor registry data are often incomplete. However, once it is established that the abstracting done by the registry is of acceptable quality if the dataset is limited primarily to disease-related items, then more of the information can be reliably obtained from the tumor registry without having to consult the medical record.

Clearly, quality control procedures are an important aspect of a registry operation and quality control standards must be continuously monitored. Some quality control procedures can be included in the data processing procedures as we did in the pilot study. These should be installed as the registry program is implemented. But quality control should be part of each aspect of the registry operation so that whatever data are collected are valid and reliable.

Follow-up: We recommend that only passive follow-up be initiated. This involves primarily linking the data in the registry with the death certificate data. An annual or periodic check against the National Death Index for cases that may die outside the state should be part of the registry program. Extensive active follow-up information should be collected only for special studies.

COST ESTIMATES FOR A STATEWIDE CANCER REGISTRY

The current ECI Cancer Surveillance Pilot Study followed a Cancer Surveillance Feasibility Study that was originally funded by the Illinois Institute of Natural Resources (INR). This feasibility study (INR Project No. 90.026) was funded for the period September 11, 1980 through August 15, 1981 for the amount of $34,706. The results of that study were published in INR Document No. 81/30 (October, 1981). A Feasibility Study of Cancer Surveillance in Illinois[2] by Richard B. Warnecke, Ph.D. and Craig B. Dickson, M.P.H. The report detailed our recommendation that a population-based cancer registry is the most suitable approach for Illinois to monitor its cancer experience. It further recommended that a pilot study be carried out in a specific region of the state to examine the feasibility of the proposed methodology.

In November, 1981 a contract (Project No. 90.026 SA1) was awarded by the Institute of Natural Resources to the ICC to conduct a cancer surveillance pilot study in East Central Illinois. The contract period ran through June 30, 1982 and was for the amount of $24,636. Concurrently a $4,000 contract for computer support and typing services was awarded to ICC from the Illinois Department of Public Health. This initial phase of the project was subsequently extended two months through August 31, 1982 at an added cost of $14,000.

The new Department of Energy and Natural Resources was created and replaced the INR. The contract was continued as DENR contract No. E45 for the period 11/12/82 through 8/31/83 for $66,832. An additional contract for

$62,910 continued the project from September 1, 1983 through August 31, 1984. The time for completion was extended through August 31, 1984 without additional funds. On April 17, 1984 the Illinois Department of Public Health entered into a second agreement with the ICC to continue funding the cancer registry pilot study through September 30, 1984. The amount of this final phase was $23,000.

The total 35 month project period can be divided into two stages; an eight month start-up phase and a 27 month operational phase. During the start-up phase about 23 percent of the budget was expended; 77 percent was spent for operations.

Costs for abstracting and entering patient data into a computerized system in the pilot study are estimated at about $44.30 per case. During 1982, 1,886 unduplicated cancer patient data forms were entered into the pilot registry. These cases were obtained from 13 hospitals. Since the data for 1983 are still being reviewed and computerized, we estimate the number of cases to be abstracted and coded at 1,500. Therefore, about 3,386 cancer patient data forms will have been abstracted, coded and entered onto the computer by the conclusion of the project. Using the total operational budget of $150,000, the per case cost is determined by dividing $150,000 by 3,386; the result is $44.30 per case.

However, the cost of expanding the registry from East Central Illinois to the entire state can not be extrapolated directly from the per case costs experienced in this pilot study. There are several reasons for caution in generalizing. First, in areas where there is a greater patient density, such as in Chicago, the costs may be less because travel is not as extensive. On the other hand there are more patients in many more institutions and hence, the frequency of case ascertainment may have to be increased, thus increasing the costs. We also recommend that less data be collected in a statewide registry than were collected in the pilot study. If this recommendation is accepted the costs of abstracting will be substantially reduced. Moreover, senior staff time required to develop and maintain liaison with the participating hospitals, specifically the time of Dr. Alexander, will not be required because participation will be mandatory.

A more realistic estimate of the costs of a statewide cancer surveillance system in Illinois can be made based on the following assumptions.

-mandatory statewide reporting will become law in Illinois before the surveillance system is established;

-data will be abstracted and coded by trained abstractors supervised by the registry at individual institutions rather than centrally;

-data entry will take place centrally at the registry headquarters;

-passive follow-up procedures will be initiated;

-a reduced data set will be used eliminating many of the patient-related and disease-related items which are costly to obtain;

-funds for research and education will not be part of the registry budget;

-costs of office space and equipment (desks, chairs, files, etc.) are not part of the operational budget.

An estimated budget based on these assumptions is attached (Table 8). Using the estimate of 44,000 cases per year the per case cost would be $22.07. Year 2 is probably the best basis for estimating the operational costs because year 1 contains some set-up costs, chiefly those required for purchase of a computer on which to operate the system.

It is clear from the experience of most registries that a dedicated computer for managing the data is essential. Our estimate of these costs is based on the purchase cost of a Zilog Model 31 CPU. There may be other computers that are more reasonable and/or more efficient. Moreover, the budget assumes that the costs of analyzing the data will be borne by research projects and the analysis will not be carried out on the registry computer. This item is therefore highly flexible.

A second costly item is the abstractors. This cost too, may have to be reconsidered depending on the results of the last phase of the pilot which involves the investigation of the use of the discharge data system for case finding. Depending on how discharge data can be used the need for abstracting may change considerably. However, assuming that abstractors will be needed in some capacity to obtain data, we used the following assumptions to estimate the costs.

We began with the assumption that 44,000 new cases would occur in the Illinois population per year. Using the average ratio developed by SEER of cancer admissions to cancer cases of 1.49 we estimated that 65,560 cancer admissions would have to be checked each year. The average ratio of full-time equivalent abstractor-coder per 1,000 cases used by SEER is .8. However, the Illinois system will differ from the SEER system in two ways.

Table 8

ESTIMATED BUDGET

ILLINOIS STATEWIDE CANCER SURVEILLANCE SYSTEM

PERSONNEL		Year 1	Year 2
Position	% Effort		
Director of Registry	100%	$ 65,000	$ 67,000
Data Collection Supervisor	100%	36,000	38,000
System Analyst/Programmer	100%	34,000	36,000
Director of Quality Control	100%	30,000	32,000
Chief Abstractor	100%	21,000	23,000
Programmer	100%	23,000	24,000
Vital Records Clerk	100%	-	15,000
Abstractors (22 individuals)	100%	374,000	396,400
Data Entry Clerk (2 individuals)	100%	28,000	30,000
Data Entry Clerk	100%	-	14,000
Secretaries (2 individuals)	100%	26,000	28,000
	Subtotal	$637,000	$703,000
FRINGE BENEFITS @ 19%		$121,030	$133,570
EQUIPMENT:			
Computer			
-Zilog Model 31 CPU		$ 38,610	$ -
-9 Track Tape Drive		8,955	-
-PRZ Printer		7,605	-
-Remote Job Entry		5,000	-
-Data Base Management System		5,000	-
-CRT Terminal: 10 @ $750 each		7,500	750
	Subtotal	$ 72,670	$ 750
SUPPLIES:			
General Office		$ 5,000	$ 5,500
Computer Related		3,500	3,000
	Subtotal	$ 8,500	$ 8,500

Table 8 (Continued)

TRAVEL:	Year 1	Year 2
Local		
-2 trips/week, Abstractor @ 150 mi/trip x 22.5¢ mi.	$ 77,220	$ 77,220
-1 trip/week, Chief Abstractor @ 150 mi/trip x 22.5¢ mi.	1,755	1,755
-1 trip/week, Data Collection Super. @ 150 mi/trip x 22.5¢ mi.	1,755	1,755
-1 trip/week, Director Quality Control @ 150 mi/trip x 22.5¢ mi.	1,755	1,755
Domestic		
-2 trips/Principal Investigator to National Meetings @ $750/trip	1,500	1,500
Subtotal	$ 83,985	$ 83,985
OTHER EXPENSES:		
-Computer Maintenance	$ 7,000	$ 7,000
-Computer Installation	2,000	-
-Software Subscription	2,000	2,000
-IBM Computer Use	5,000	5,000
-Computer Consultant 5 days @ $400/day	2,000	2,000
-Telephones: 6 units @ $55/mo. each, equipment and use charges;	3,960	4,356
$122 Installation/Unit	732	-
-Copying: $800/mo.	9,600	10,560
-Publications, Subscription, Dues	1,000	1,100
-Printing	4,000	4,400
-Training Costs - 3 day workshop for abstractors in Chicago		
-Transportation, 1 trip x 22 abstractors @ 150 mi/trip x 22.5¢ mi.	750	-
-Hotel, $65/night x 22 abstractors x 3 nights	4,290	-
-Per Diem, $25/day x 22 abstractors x 3 days	1,650	-
-Meeting Room	500	-
-Miscellaneous	5,000	5,000
Subtotal	$ 47,832	$ 41,416
TOTAL COST	$971,017	$971,221

First, Illinois will collect less data on each patient than is collected by SEER if our recommendations regarding the dataset are accepted. Second SEER uses an active follow-up procedure and we recommend Illinois adopt passive follow-up. We estimate that these two factors will reduce the abstracting factor from .8 to .5 per 1,000. Applying this factor to the expected 44,000 new cases in Illinois, it is estimated that approximately 22 abstractors will be needed; ten in the Chicago SMSA, two in Springfield and the rest located throughout the state. Moreover, since the hospitals outside of the metropolitan areas are widely scattered, we assume that travel costs will be another major budget item.

It should be noted that even with the changes in the proposed registry, implementing a population-based surveillance system in Illinois is going to be a costly procedure. In concluding this section, we would like to offer one other recommendation. As part of the deficit reduction package President Reagan has just signed, the tax on cigarettes will be reduced by eight cents a package. This tax has been paid by smokers for several years and would probably be accepted with little resistance if reinstituted in Illinois. The revenue from such a tax could not only support a registry but could undoubtedly support the development of an entire program addressing hazardous wastes, smoking, and cancer. It is worth consideration and is being highly recommended by the American Public Health Association.

SUMMARY

In summary, this project has demonstrated that a statewide cancer registry is feasible in Illinois and would cost about $22 per case to operate. This cost estimate assumes a limited number of items will be abstracted on each case, that follow-up will be passive and depend upon linkage to death certificates, and that the discharge data will be used for case ascertainment but that abstracting at each hospital will be required.

VIII. REFERENCES

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3. A STUDY FOR THE ESTABLISHMENT OF A STATEWIDE CANCER INCIDENCE REGISTRY University of Pennsylvania Staff: Anita K. Bahn, Janel Ellis Cherry, Judith L. Kinman, Ira Rosenwaike, Marie A. Marino.

4. FLORIDA CANCER DATA SYSTEM G. Burton Seibert.

5. A PLAN FOR THE BALTIMORE CITY CANCER REGISTRY by the Johns Hopkins Oncology Center Planning Group: Raymond E. Lenhard Jr., Raymond Seltser, John P. Enterline, Bruce I. Blu, Herbert L. Elliott, Anne L. Kammer, Joyce M. Kane, Betty K. White, Liliam E. Trociuk.

6. Feasibility Study of a Statewide Pathology-Based Cancer Surveillance System in Minnesota 1982, Minnesota Department of Health, 717 S.E. Delaware St. Minneapolis, Minnesota.

7. Cancer Data System, The Greater Cleveland Hospital Association, Euclid Avenue, Cleveland, Ohio 44115.

8. International Classification of Diseases for Oncology (ICD-0) World Health Organization, Geneva, Switzerland.

9. Cancer Data Acquisition Manual, Illinois Cancer Council - April 1982.

Appendix A

PERSONNEL AND FACILITIES

A. Personnel and Facilities

Richard B. Warnecke, Ph.D., Principal Investigator

As Principal Investigator, Dr. Warnecke has supervised all aspects of the pilot study. He has assisted Dr. Alexander in efforts to expand the study and develop additional sources of funding.

Arlene N. Alexander, M.D., M.P.H., Project Manager

Dr. Alexander has worked with the hospitals participating in the registry and maintained contact with nonparticipants in an effort to demonstrate the benefits of the program. She has also worked with ICC staff in refining methods of data collection and data processing. Dr. Alexander, in conjunction with Ms. Tuteur and Ms. Miller, has been involved with the quality control of data abstracted from patient records at participating hospitals.

Dr. Alexander has attended and participated in various regional and state-wide meetings concerning professionals' continuing education, health care and delivery of services. This was viewed as a means for the ICC to promote awareness of the registry and support of its goals and to encourage use of the cancer registry data.

With support from Dr. Warnecke, Dr. Alexander has explored possible alternative funding sources and the issue of cancer reportability.

Anne Paxton-Stolar, M.B.A. Administrator

Ms. Paxton-Stolar is the Administrator of the ICC and has had primary responsibility for the financial and administrative needs of this program. She has acted as a business liaison between the ICC staff and

DENR. She has approved all expenditures under this program and met necessary internal budget needs. Ms. Paxton-Stolar also assisted Drs. Warnecke and Alexander in identifying and soliciting additional funding sources.

Diane Tuteur, R.R.A., C.T.R., Quality Control Manager

Ms. Tuteur has been responsible for implementing and monitoring quality control procedures for this program. Ms. Tuteur has also been responsible for forms control at the ICC, as well as abstractor training.

Lisa Miller, Abstractor

Ms. Miller, who replaced Patricia Hoffman, has continued her duties of record abstracting at participating hospitals. Where necessary, Ms. Miller also trained hospital-employed abstractors in proper abstracting techniques. She has also assisted Dr. Alexander and other ICC staff in improving data collection techniques.

Andrius Kubilius, Programmer

Mr. Kubilius is responsible for maintaining all computer programs and files necessary to the program. He also assists in all computer analyses of data collected.

Teresa Dunbar, Data Entry Clerk

Ms. Dunbar has been responsible for the data entry of cancer patient case abstracts. She assists Mr. Kubilius in program editing and maintenance of computer files.

The headquarters of the Comprehensive Cancer Center, the Illinois Cancer Council (ICC), located in suite 700 at 36 South Wabash Avenue in Chicago is the central office for the study. The field office is located in the Illinois Department of Public Health's (IDPH) regional office at 2125 South First Street in Champaign, Illinois. The IDPH regional office has provided office space, desks, telephones, answering service, office supplies, photocopying, and secretarial help under the supervision of Barbara Honaker, the Administrative Assistant.

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16. Abstract (Limit: 200 words)

Cancer surveillance programs are being established in many states in order to determine the magnitude of the cancer experience at a level where policy and health programs can respond to restrain its occurence and modify its effects. Illinois has not developed a cancer surveillance program so there is no precise count of how many new cancer patients are diagnosed in the Illinois population each year. From the experience of other similar states and based on data obtained through the Surveillance, Epidemilogy and End Results (SEER) program at the National Cancer Institute (NCI) we estimate that about 44,000 new cases will be diagnosed among the Illinois population in 1984.

To address the need to know more about the experience of cancer among the population of Illinois, the Illinois Department of Energy and Natural Resources, working together with the Illinois Department of Public Health contracted with the Illinois Cancer Council in 1980-81 to conduct a feasibility study to determine whether cancer reporting could be carried out in Illinois and which of several possible methods of case ascertainment would be most effective. Based on the experience of others and our review of the feasibility of each approach, it was recommended that the case registration approach be subjected to further study. Beginning in November 1981, the Departments supported the Cancer Surveillance Pilot Study for East Central Illinois.

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